

**ANNUAL REPORT  
OF THE INDIANA  
COMMISSION ON MENTAL  
RETARDATION AND  
DEVELOPMENTAL DISABILITIES**



**Indiana Legislative Services Agency  
200 W. Washington Street, Suite 301  
Indianapolis, Indiana 46204**

**November, 2001**

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# INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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A copy of this report is available on the Internet. Reports, minutes, and notices are organized by committee. This report and other documents for this Committee can be accessed from the General Assembly Homepage at <http://www.state.in.us/legislative/>.

## **I. STATUTORY AND LEGISLATIVE COUNCIL DIRECTIVES**

The Indiana Commission on Mental Retardation and Developmental Disabilities (MRDD) was established by P.L. 78-1994 to do the following: (1) develop a long-range plan for community-based services for the developmentally disabled; and (2) review, make recommendations, and monitor changes regarding services to the mentally retarded and developmentally disabled population. P.L. 245-1997 amended the original legislation, extending the life of the Commission to January 1, 2001.

P.L. 272-1999 further extended the life of the Commission to January 1, 2005, and added the following responsibilities: (1) review and make recommendations regarding the implementation of the comprehensive plan prepared by the Developmental Disabilities Task Force (created by P.L. 245-1997, SEC. 1 and also called the "317 Task Force"); and (2) review and make recommendations regarding the development by the Division of Disability, Aging, and Rehabilitative Services of a statewide plan to address quality assurance in community-based services. P.L. 242-2001 added an annual review of the Infants and Toddlers with Disabilities Program (i.e., "First Steps") to the Commission's duties.

In Legislative Council Resolution 01-2, the Legislative Council requested that the Commission study the economic impact of the closing of Muscatatuck State Developmental Center.

## **II. INTRODUCTION AND REASONS FOR STUDY**

The creation of the MRDD Commission in P.L. 78-1994 was a response to the need for long-range planning and the determination of needs of people with developmental disabilities.

## **III. SUMMARY OF WORK PROGRAM**

The Commission met five times during the 2001 interim.

The first meeting of the Commission was held at the State House on August 30, 2001. Discussion topics at the meeting included: (1) organizational matters; (2) update on the operation of the Family and Social Services Administration; (3) United States Department of Justice visits to Muscatatuck and Fort Wayne State Developmental Centers; and (4) implementation of 317 Task Force Plan, waiver rewrites, and waiting lists.

The second meeting of the Commission was held at the State House on September 5, 2001. The topic of discussion at this meeting was the Infants and Toddlers with Disabilities Program (i.e., "First Steps").

The third meeting of the Commission was held at the Muscatatuck State Developmental Center chapel on September 27, 2001. The topic of discussion at this meeting was the procedure for and economic impact of the closure of the center.

The fourth meeting of the Commission was held at the State House on October 4, 2001. Discussion topics at the meeting included: (1) *Olmstead*; (2) Governor's Council on State-Operated Care Facilities; (3) mortality review process; (4) group homes; and (5) First Steps and special education.

The fifth meeting of the Commission was held at the State House on October 24, 2001. At this meeting, the Commission discussed its recommendations and proposed legislation.

#### **IV. SUMMARY OF TESTIMONY**

Acronyms used in this report are as follows:

- CMS - United States Centers for Medicare and Medicaid Services (formerly known as the Health Care Financing Administration or HCFA)
- DD - developmental disabilities
- DDARS - Division of Disability, Aging, and Rehabilitative Services, FSSA
- DFC - Division of Family and Children, FSSA
- DOJ - United States Department of Justice
- FSSA - Family and Social Services Administration
- FWSDC - Fort Wayne State Developmental Center
- ICF/MR - intermediate care facility for the mentally retarded
- ISDH - Indiana State Department of Health
- MSDC - Muscatatuck State Developmental Center
- MSH - Madison State Hospital
- TANF - Temporary Assistance to Needy Families

The Commission heard testimony from FSSA personnel and various other interested parties regarding the following issues:

##### *(1) FSSA Update*

- MSDC has been fully recertified for federal Medicaid funding.
- The process of closing MSDC has begun. (See *Closure of MSDC* below for further information.)
- In response to a call from the Governor for state agencies to identify areas in which to save money, FSSA has established \$28.8 million in reserves for state fiscal year 2002. These funds come from a combination of administrative cost-cutting, spending of other reserves, slow down of planned expansions, some program reductions, and revenue enhancements.
- FSSA has entered into a settlement agreement with the DOJ regarding the operation of MSDC and FWSDC. Under this agreement, which addresses issues such as staffing ratios and quality assurance processes, the DOJ may continue to monitor MSDC, FWSDC, and residents who move out of those centers until May, 2003. The DOJ is not pushing FSSA to close either center, but is aggressively urging the state to assure that the services provided to individuals with disabilities both in the centers and in the community be of the highest quality possible.
- CMS approved FSSA's application for a new DD Medicaid waiver, effective October 1, 2001.

This waiver, which replaces the previous ICF/MR waiver, should allow FSSA to move approximately 1,500 individuals from fully funded state services to Medicaid waiver services, thus freeing up state funds to serve individuals on the waiver waiting lists. This new waiver includes approximately 2,000 slots and the ability to add more slots as funding becomes available. Under this waiver, Medicaid will provide reimbursement for health care management, case management, and transportation.

- FSSA is working on implementing SEA 215-2001 regarding self-directed care for individuals with disabilities. The autism, medically fragile children, and aged and disabled Medicaid waivers are being amended to include self-directed care.
- The state's Medicaid plan has been amended to include case management services for individuals with developmental disabilities who meet the state's Medicaid eligibility requirements but who are on a waiver waiting list.
- FSSA is amending the autism waiver to include coverage for applied behavioral analysis and to add 100 slots per year for each year of the next two years.
- Almost 2,400 individuals with disabilities were served through the use of the \$64 million that was appropriated to FSSA in the 1999-2001 budget, as compared to the 1,757 individuals that FSSA estimated would be served through these funds.
- Others issues that FSSA is continuing to work on include investigating ways to increase payment rates to direct care providers and to increase the availability of qualified, well-trained care givers.

## *(2) Olmstead/Governor's Council on State-Operated Care Facilities*

- In response to the United States Supreme Court's opinion in the *Olmstead* case (which held that individuals with disabilities have the right to live in the least restrictive, most integrated setting possible), FSSA issued a report on the state's status in providing care to individuals with disabilities. The main recommendation of this report was the formation of a Community Choice Commission to establish Indiana's long-term plan for providing community services to individuals with disabilities. FSSA is in the process of establishing this commission.
- The *Olmstead* decision will continue to have an impact regardless of the closure of MSDC, as the court's decision applies to services provided to individuals with disabilities in community settings as well as in institutional settings.
- In 1999, Governor O'Bannon created the Council on State-Operated Care Facilities to ensure provision of high quality, cost-efficient care in the eleven care facilities operated by FSSA and the ISDH. The Council's final report recommended that services to individuals with mental illness and mental retardation/developmental disabilities be regionalized, with the state divided into eight regions.
- The first regional services center will be located in the southeast part of the state. It is anticipated that the southeast region will have 150 beds, 90 for individuals with serious mental illness and 60 for individuals with mental retardation/developmental disabilities. One location under consideration for the southeast regional center is the current MSH.
- The number of beds to be located in each region will vary and will be based on a particular region's needs and resources.

### *(3) Closure of Muscatatuck State Developmental Center (MSDC)*

- All parties involved with the closure of MSDC agree that the number one priority in the closure plan is the well-being of the center's residents.
- The closure of MSDC has caused great concern among the center's residents, their families and advocates, and employees and in the surrounding community. Much of the concern has been focused on the perceived political nature of the decision to close the center and the proposed time frame for closure (i.e., June 30, 2003), as well as its potential traumatic impact on residents, many of whom are profoundly disabled and/or medically fragile.
- A lawsuit to prevent the closure of MSDC has been filed on behalf of the residents of the center.
- There is a great deal of concern regarding whether there is an adequate number of community service providers and well-trained care givers to provide the care in the community that will be needed by individuals who are moved out of MSDC.
- MSDC employees and parents of MSDC families are frustrated over what they believe to be a lack of interest by FSSA in their concerns over closure of the center. Additionally, employees of the center often feel reluctant to talk about their concerns due to fear of being harassed or fired.
- There are currently no specific plans regarding the future of the physical location of MSDC. FSSA and the state Department of Administration are conducting engineering and infrastructure surveys of the facility, the results of which will be used by the state Department of Commerce to find viable alternative uses for the property.
- The closure of MSDC, which employed 1,148 individuals at the time that closure was announced, will have a profound impact on the economy of Jennings County, particularly if the state chooses to locate the proposed Southeast regional center outside of the county.
- FSSA, the state Department of Workforce Development, and the Jennings County Economic Council are assisting MSDC employees in training for and finding new employment. Some individuals who testified indicated that the proposed closure date is not anticipated to provide enough time to find alternative employment for all employees.

### *(4) Mortality Review*

- FSSA implemented a mortality review committee in February, 2000. The purpose of the committee is to review the deaths of residents in state developmental centers, private ICF/MRs, and community settings.
- Since its implementation, the mortality review committee has reviewed and closed 122 cases. The average review time for a case is three months.
- Based on its review of cases, the committee makes recommendations that can be either systemic or provider specific. One systemic recommendation of the committee is that providers make sure that their employees who provide care to a client are familiar with the client's particular needs.

### *(5) Group Homes*

- The ISDH is the agency responsible for enforcing federal regulations regarding group homes.
- Within the past two years, CMS had instructed the ISDH to strictly enforce regulations W197 and W198 regarding active treatment (i.e., treatment aimed at teaching an individual the skills necessary to live in a more independent setting) in group homes.
- The result of an ISDH finding that an individual in a group home no longer needs active

treatment is that the group home loses its certification for Medicaid payments unless the individual is moved out of the group home.

- Historically, when a W197/W198 citation has been issued, an individual has had three months in which to relocate. After discussions between the ISDH, CMS, and FSSA, that time has been extended to approximately seven months.
- Over 90% of individuals who are required to move out of a group home due to W197/W198 citations are eligible for services through a Medicaid waiver, if a slot is available.
- Individuals relocated from a group home who require 24-hour care still receive that care in their new location.
- A lack of understanding regarding what type of care an individual will receive once relocated from a group home is the cause of a large portion of the stress surrounding W197/W198 issues.
- SEA 375-2001 allows more than four individuals with W197/W198 findings to remain in a group home for up to one year while the facility converts from a group home to a supported living setting.

*(6) Infants and Toddlers with Disabilities Program ("First Steps")/Special Education*

- First Steps, which has been in existence since 1986, provides early intervention services to children up to three years of age who have or are at risk of having developmental disabilities or delays.
- Indiana's First Steps program has the second broadest eligibility criteria in the nation. In 2001, the program has served approximately 17,000 children.
- Several funding sources, most notably TANF funds, are used for First Steps. State funds, of which the program uses approximately \$5 to \$6 million dollars annually, are used after all other available funding sources.
- The average cost for providing direct services to a First Steps child in state fiscal year 2001 was approximately \$2,800.
- As required by state legislation enacted in 2001, DFC is currently working on implementing a cost participation program for First Steps. This program is required to be in place by July 1, 2002. The potential cost savings of a cost participation program are the subject of much dispute.
- A survey of the First Steps program conducted in early 2001 made 17 specific recommendations regarding program controls and accountability. Some of these recommendations include reexamining the role of the service coordinator, regionalizing system points of entry, and prohibiting a service provider from participating in the assessment of a child's service needs and providing some of those same services to the child.
- Indiana requires more training for First Steps service coordinators than any other state.
- There are three options available for a parent of a First Steps child to contest an action under the program: (1) complaint investigation by FSSA; (2) mediation; and (3) due process hearing.
- Approximately 23% of First Steps children go on to participate in special education programs in school. The average annual cost of special education for a child is \$13,000.
- First Steps differs from school-based special education in many ways, including the following:
  - First Steps looks primarily at a child's developmental needs while special education focuses on the child's educational needs.
  - First Steps has much broader eligibility criteria than special education.



- Under First Steps, a child's family chooses the child's service providers. In special education, the school corporation chooses the providers.
- Services under First Steps are provided in a "natural environment," often the child's home. In special education, the student may be required to go to a location other than the school in order to receive services.
- First Steps services are provided on a year-round basis, while special education is provided mainly during the school year.
- First Steps services are reimbursed on a fee-for-service basis, while a single fee is paid for all special education services needed by a child, regardless of the actual cost.

## **V. COMMITTEE FINDINGS AND RECOMMENDATIONS**

The Commission made no findings of fact.

The Commission made the following recommendations:

- The Commission urges FSSA to work with all interested parties to study the issues surrounding the implementation of a system of checks and balances between services needed by a child in the First Steps program and the services authorized.
- The Commission approved PD 3438 by a vote of 8-0. This draft changes the Commission from a noncode to a statutory commission, making the following changes: (1) specifies that the term of a lay member is three years; (2) requires the Governor to fill a lay member vacancy within 10 days after the vacancy occurs; and (3) provides that under certain conditions the term of a lay member continues until a successor is appointed. The draft also provides that the Commission operates under the policies governing study committees adopted by the Legislative Council, repeals noncode provisions establishing the Commission and its duties, and "grandfathers" current lay members until the expiration of their terms in 2004.
- The Commission approved PD 3439, as amended, by a vote of 8-0. This draft prohibits, until January 1, 2004, the relocation of a MSDC resident to an alternative residential setting unless the alternative residential setting is: (1) appropriate based on the individual's capabilities and needs; and (2) acceptable to the individual or the individual's representative. This draft also requires DDARS, beginning March 1, 2002, to provide the Commission with a quarterly report regarding the status of the MSDC closure.
- The Commission approved PD 3440 by a vote of 8-0. This draft requires DDARS' Bureau of Developmental Disabilities Services, when contracting for the provision of services to individuals with disabilities, to contract with governmental units and other public or private organizations or individuals that are accredited by certain organizations.

## WITNESS LIST

- Jerry Allen, First Steps Central Reimbursement Office Project Director, Financial Management, Family and Social Services Administration
- Denise Arland, Chairperson, Interagency Coordinating Council
- Alison Becker, Deputy Director, Fiscal Services, Division of Disability, Aging, and Rehabilitative Services, Family and Social Services Administration
- Juman Bruce, Superintendent, Muscatatuck State Developmental Center
- Travis Campbell, Executive Director, Jennings County Economic Development Council
- Gerald Coleman, Assistant Commissioner, Health Care Regulatory Services, Indiana State Department of Health
- Patty Cook, Director of Social Services, Muscatatuck State Developmental Center
- Steve Cook, Deputy Director, Bureau of Developmental Disabilities Services, Division of Disability, Aging, and Rehabilitative Services, Family and Social Services Administration
- John Dickerson, Executive Director, The ARC of Indiana
- Representative Cleo Duncan, District 67 (Decatur, Ripley, Switzerland)
- Frances Egner, parent of Muscatatuck State Developmental Center resident
- Maureen Greer, Assistant Deputy Director, Child Development, Division of Family and Children, Family and Social Services Administration
- John G. Hall, Mayor, North Vernon
- John Hamilton, Secretary, Family and Social Services Administration
- Trevor Lane, Jennings County Economic Development Council
- Representative Markt L. Lytle, District 69 (Jackson, Jefferson, Jennings)
- Bob Marra, Associate Superintendent, Indiana Department of Education
- Chuck Martindale, Indiana Department of Commerce
- Frank Migliano, President, Muscatatuck State Developmental Center ARC
- Costa Miller, Executive Director, Indiana Association of Rehabilitation Facilities
- Mary Mills, Muscatatuck State Developmental Center employee
- Tracy Mitchell, Bradley and Associates
- Dan Mohnke, consultant, Division of Disability, Aging, and Rehabilitative Services, Family and Social Services Administration
- Chris Newman, Director, Bureau of Quality Improvement Services, Division of Disability, Aging, and Rehabilitative Services, Family and Social Services

## Administration

- Senator Johnny Nugent, District 43  
(Dearborn, Ohio, Ripley, Union, Franklin,  
Jefferson, Jennings, Switzerland )
- Susan Preble, Legislative Liaison, Family  
and Social Services Administration
- Suzann Shackleton, licensed social worker,  
Warren County
- Marilyn Schultz, Director, Division of  
Disability, Aging, and Rehabilitative  
Services, Family and Social Services  
Administration
- Pat Vercauteren, Indiana Department of  
Workforce Development